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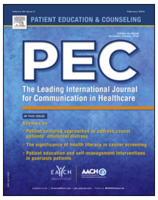

Review

End-of-life expectations and experiences among nursing home patients and their relatives—A synthesis of qualitative studies

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ABSTRACT

Objective: Synthesize research about patients' and relatives' expectations and experiences on how doctors can improve end-of-life care in nursing homes.

Methods: We systematically searched qualitative studies in English in seven databases (Medline, Embase, PsycINFO, CINAHL, Ageline, Cochrane Systematic Reviews and Cochrane Trials). We included 14 publications in the analysis with meta-ethnography.

Results: Patients and families emphasized the importance of health personnel anticipating illness trajectories and recognizing the information and palliation needed. Family members who became proxy decision-makers reported uncertainty and distress when guidance from health personnel was lacking. They worried about staff shortage and emphasized doctor availability. Relatives and health personnel seldom recognized patients' ability to consent, and patients' preferences were not always recognized.

Conclusion: Nursing home patients and their relatives wanted doctors more involved in end-of-life care. They expected doctors to acknowledge their preferences and provide guidance and symptom relief.

Practice implications: High-quality end-of-life care in nursing homes relies on organization, funding and skilled staff, including available doctors who are able to recognize illness trajectories and perform individualized Advance Care Planning.

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1. Introduction

In recent decades, nursing homes have become a more frequent place for dying by comparison with hospitals. In Norway, 47% of all the people dying in 2013 died in nursing homes [1]. The end of life has been described as "an extended period of one to two years during which the patient/family and health professionals become aware of the life-limiting nature of their illness" [2]. Caring for dying people in nursing homes comprises organizational, professional and existential elements [3]. Most nursing homes are nurse-led, with limited doctor availability. Doctors are responsible for the medical aspects of end-of-life care such as initiating and withdrawing drug treatment. The treatment goals are shifting from cure to symptom relief towards the end of life [4], which may challenge doctors' professional attitudes [5].

Patients admitted to long-term care in nursing home probably realize that they will stay until they die. Many of them have reflected on their own death in terms of existential thoughts and concerns about suffering during the terminal phase [6,7]. These patients may have considered whether or not they would opt for life-prolonging treatment. Family members often sense the forthcoming death of their loved one. If patients and their families have not discussed this matter, diverging expectations may emerge when the patients become ill and decisions about life-sustaining treatment have to be made [8,9]. Dialogues between staff members, patients and their relatives about the end of life are prerequisites for individual decision-making [10,11], but health professionals often experience this as being difficult [12,13]. Knowledge is still scarce regarding the preconditions for high-quality end-of-life care in these institutions [14]. A priori knowledge about common questions and concerns among patients and relatives can make doctors more confident about initiating such preparatory conversations.

As doctors with extensive experience from general practice, nursing homes, research and work with death close at hand in hospitals, we share an interest in patient focus, comprehensive health care and doctors' role. We are also concerned about the ways the medical culture contributes to marginality. Death is for example often viewed as defeat in the medical tradition, and thus becomes a marginalized issue. We would, however, claim that death is a natural part of life and should therefore not belong to a marginal domain of medicine. This standpoint is an essential element of our professional perspectives. We therefore wanted to develop knowledge useful for nursing home doctors in providing medical care for patients and relatives towards the end of life.

The aim of this study was to identify and synthesize qualitative research findings about nursing home patients' and relatives' expectations and experiences on how doctors can contribute to quality end-of-life care.

2. Methods

We synthesized qualitative studies, aiming at developing additional knowledge by systematically and comprehensively interpreting previous research. We used meta-ethnography as described by Noblit and Hare [15], a strategy including seven steps presented below. This commonly used method is suitable for systematically analyzing and synthesizing qualitative research [16–18].

2.1. Search strategy

First we defined the aim of the study (step 1), with inclusion and exclusion criteria for primary studies to be analyzed (step 2). We systematically searched seven databases from September 17 to October 9, 2012 including the search terms death, nursing home and expectations entered individually and in combination, in full spelling and truncated (Table 1). We then filtered for methods, limiting to qualitative studies.

2.2. Inclusion criteria

We initially identified 834 hits. We excluded duplicates, reviews, book chapters, theoretical papers, dissertations, comments and editorials. Two authors (AF and MAS) independently reviewed the titles and abstracts of the remaining 505 unique publications according to our inclusion criteria, comprising qualitative studies in English presenting relevant findings about patients' and relatives' expectations and experiences concerning the end of life in nursing homes. We included surveys if qualitative methods had been conducted on relevant subgroups of a sample. We excluded studies on the perspectives of health personnel or studies focusing on hospital, hospice or home care. We excluded quantitative studies because expectations and experiences are subjective phenomena that cannot be explored in depth through numbers and statistical analysis. We screened 72 publications in full text, assessing relevance, resulting in 20 publications eligible for systematic review.

2.3. Quality assessment

AF and KM assessed the quality of the 20 eligible publications independently, according to a systematic and acknowledged checklist for qualitative studies evaluating objectives, reflexivity, design, data collection and sampling, theoretical framework, methods of analysis, results, discussion and presentation [19]. Through negotiations, we excluded six publications because they lacked reflexivity and presented the results indistinctly. We included the remaining 14 publications for synthesis in our meta-ethnography (Fig. 1).

Table 1
Search strategy.

Text words entered individually, in combination, in full spelling and truncated: death; dying; end-of-life; palliative; terminal; nursing home; home for the aged; expectation; wish; fear; anxiety; forecasting; living will; advance directive; emotion; hope; perception; attitude to death; attitude to health; attitude to life; end-of-life experience; experience	
Medline (Ovid)	1946 to September 17, 2012
EMBASE (Ovid)	1974 to October 8, 2012
PsycINFO (Ovid)	1806 to week 4 of September 2012
CINAHL (Ebsco)	1981 to October 8, 2012
Ageline (Ebsco)	1978 to October 8, 2012
Cochrane Systematic Reviews (Wiley)	Issue 9 of 12, September 2012
Cochrane Trials (Wiley)	Issue 9 of 12, September 2012